

HIV

TESTS AND TREATMENTS

*information and advice
to help you make decisions*

2003 EDITION

Australian Federation of AIDS Organisations
National Association of People Living With HIV/AIDS

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www.afao.org.au

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What this booklet is about

This booklet describes the currently available antiviral drugs for the treatment and management of HIV infection. It also describes some common tests used to monitor the health of people with HIV, and how these tests can be used to help you look after your health, or make decisions about starting, stopping or changing antiviral treatments.

This booklet is for anyone with HIV who may be considering starting, stopping or changing treatment.

Who this booklet is for

This booklet is for anyone with HIV who may be considering starting, stopping or changing treatment. It is designed for all people with HIV, whether you have been recently diagnosed, or have known about your HIV positive status for some time.

The information in this book is designed to help you:

- understand how HIV antiviral treatments work, and what drugs are currently available;
- understand the different tests which might be suggested by your doctor to help monitor your health; and
- work with your doctor to come up with the most appropriate HIV treatment and management strategy for you – whether with or without antiviral drugs.

It also contains some information about:

- drug side effects and how they might be managed;
- tips and tricks for getting the most out of your drugs; and
- new developments and treatment options in the pipeline.

What this booklet does not do

This booklet is primarily concerned with HIV antiviral treatments, viral load tests and CD4 (T-cell; also called CD4 lymphocyte) tests. It is designed to update the previous edition of this popular resource with the current state of knowledge in the middle of 2003. The booklet is deliberately limited in its scope, and you are likely to find

it does not answer all your questions about treating and managing HIV. Because information about HIV is becoming much more complex and comprehensive, it is virtually impossible for any single resource to cover all the issues about living with HIV for all positive people.

This booklet aims to take you through some of the choices, but in the end they are your choices to make.

This booklet will not cover the following issues:

- prophylactic drugs or treatments for HIV-related opportunistic illnesses;
- the treatment, prevention and management of specific side effects;
- depression and other mental health and psychosocial issues for people living with HIV;
- complementary or alternative therapies;
- co-infection with hepatitis C;
- pregnancy, breast-feeding or treatments for HIV positive children;
- injecting drug use and HIV;
- detailed strategies for choosing a GP.

These issues are well-covered by a range of existing publications which are available through AIDS Councils and other organisations or online at www.afao.org.au.

The information contained in this booklet is very general. It is not intended to direct you towards or promote any particular drugs, drug combinations, tests or treatments. You won't find an answer to the question: 'Which particular combination of drugs should I be taking?' No two people experience living with HIV in the same way. People respond differently to HIV treatments and combinations, and this is often difficult to predict. All decisions about how you treat and manage HIV infection should be discussed with your doctor. Ultimately, treating or managing HIV is a very personal decision. This booklet aims to take you through some of the choices, but in the end they are your choices to make.

The basics of HIV

Over the past twenty years, there have been a number of changes in the ways HIV infection is understood and managed. These changes have led to great improvements in treatment and management, and have greatly increased the options available. Since the advent of Highly Active Anti-Retroviral Treatment (HAART) involving combinations of three or more drugs deaths from AIDS have dramatically declined, and people with HIV on treatments have a much longer life expectancy.

There are a number of changes which have led to these improvements.

- We have a clearer understanding of how HIV works inside the body.
- The use of the viral load test measuring the amount of HIV circulating in your blood has become standard practice in Australia, Europe and North America. The results of this test can help in making treatment decisions. It can also show how well the treatments you are taking are working against HIV.
- There are now a range of antiviral drugs which act in different ways against the virus and are used in combination to treat HIV.
- We have a clearer idea of the short and long-term side effects sometimes experienced by people using these drugs, and how to manage most of them.

This booklet explains these changes and what they might mean for people living with HIV.

This booklet is primarily about treatments and tests available for HIV, and how they might work for you. However, current HIV treatments are still far from perfect, and for some people, deciding to take HIV treatments raises a number of important issues which you may need to talk about with someone. You may have questions about side effects, confidentiality, or how treatments will affect your day to day life. At the back of this booklet, there is a list of AIDS Councils where you can access counsellors and treatments officers who will be able to help you understand what taking combination therapy might mean for you.



How HIV works

The initials HIV stand for Human Immunodeficiency Virus. HIV attacks your immune system, a system of organs and cells throughout the body which usually fight off infection and keep you well. HIV affects the immune system by targeting and destroying cells which normally fight off infection. The main cells infected by HIV are called the CD4 (or T4) cells – a type of white blood cell. These cells are a major part of your immune system.

If you have been told that you are HIV positive, this means that you have been infected with HIV, and your immune system has made antibodies specifically to fight the virus. But HIV antibodies don't kill the virus. Instead, HIV continues to reproduce itself within the CD4 cells, creating 'viral copies' which cause further damage to the immune system. The more HIV is reproduced, the greater the number of new cells likely to become infected and destroyed by the virus. If your immune system is weakened, this is often described as being 'immunosuppressed' or 'immunocompromised'. This means that you are at risk of developing 'opportunistic illnesses' or other more serious diseases that are associated with AIDS.

HIV antiviral treatments are drugs which aim to stop the virus from reproducing, and so dramatically inhibit its ability to infect and destroy new cells. Sometimes people with HIV commence or restart treatments when their immune system has already been damaged. Treatments may prevent further damage and additionally allow the immune system to partially restore itself.

Natural history of HIV without HIV antiviral treatments

The following is a description of what is called the “natural history” of HIV: that is, it describes what often happens in HIV disease without antiviral treatment. It’s important to remember that antiviral treatment has significantly altered this natural history, often stalling disease

progression before immune system damage can cause AIDS or illness, and improving health and survival for many people – including people who have previously had opportunistic infections or been diagnosed with AIDS.

The natural history below describes the stages of HIV disease. It is a common,

but not universal description of HIV disease. People often think that without treatment, HIV leads inevitably to illness and AIDS.

However, even without treatments, a small but significant number of people have been able to live with HIV for a long time. This is often called being a “long-term non-progressor”.

> Stage 1 - Primary infection

When people first become infected with HIV, they may in some cases experience a flu-like illness, sometimes accompanied by a rash, which is referred to as seroconversion illness. Not all people who have been exposed to HIV will experience seroconversion illness, though: some people don’t have any symptoms at all.

> Stage 2 - Asymptomatic infection

For a number of years following infection, many people with HIV remain well and symptom-free.

For many, treatments have changed this “natural history”, improving health and survival.

> Stage 3 - Symptomatic illness

The symptoms people might experience at this stage include diarrhoea, minor skin conditions, minor oral conditions, lack of energy, night sweats, and/or persistently swollen glands.

> Stage 4 - Advanced disease (AIDS)

At this stage, HIV will have done great damage to your body’s ability to cope with illness and infection. People with AIDS experience severe symptoms, and are at risk of opportunistic illnesses.

What are opportunistic illnesses?

Opportunistic illnesses (OIs) are infections which most people have been exposed to at some point in their lives but which are suppressed by healthy immune systems. HIV can weaken a person’s immune system to the point where these infections can overcome the immune system and establish themselves as acute or ongoing infections or illnesses. Alternately, some people with weakened immune systems may become sick if exposed to an OI for the first time whereas people with stronger immune systems would not.

Some OIs can cause serious illness or can be fatal. There are effective treatments available for most OIs. You can reduce the risk from some opportunistic illnesses by taking drugs which may prevent the illness from occurring. This is called prophylaxis. In particular, if your CD4 count is under 250, or you have ever had an AIDS-defining illness, you should talk to your doctor about whether you should be taking prophylaxis. For many people, treating HIV involves using both antiviral and prophylactic treatments.

The “history” of HIV taking into account current antiviral treatments

Although treatments have improved there remain a number of unanswered questions about the impact of this on the life expectancy and long-term health of people with HIV. Prior to the advent of effective antiviral treatments it was estimated that 50% of people with HIV infection would progress to an AIDS diagnosis within 10 years.

A number of studies have attempted to estimate the average life expectancy of people with HIV presuming they have access to the most effective antiviral treatments. The average estimate is that with early access to the current antiviral treatments the number of years of expected life for people with HIV from the time they get HIV infection has doubled from the time when no treatments were available. However there is a large range in these estimates and the impact of long term and potentially serious side effects of current treatments are at this stage only rough estimates.

Prior to the advent of effective treatments the illnesses and symptoms caused by HIV were due to opportunistic illnesses and to those caused directly by HIV itself. Now the side effects of antiviral drugs – both short and long term – can be a significant cause of illness for people with HIV and may have an impact on quality of life.



Viral load

‘Viral load’ is the term used to describe the amount of HIV present in your bloodstream. Knowing how much HIV is present is an important indicator of how much your immune system is at risk of damage, how well your treatments are working, or whether you should consider starting treatments.

A viral load test is a simple blood test. The result of a test is given as the number of viral copies of HIV per millilitre of blood. A ‘copy’ is what HIV produces every time it grows inside a cell: the more copies, the more virus.

The amount of virus in your blood may range from a very small number of copies in your blood (below 50 copies per millilitre of blood) to levels in the thousands, hundreds of thousands, or even millions.

Understanding Your Viral Load results

a) ‘Undetectable’ viral load?

One result you can get back from a viral load test result is ‘undetectable’. Undetectable viral load does not mean that you have “cleared” the virus from your body. It means that HIV is present, but in very small amounts (below the capacity of tests to accurately measure: that is, below 50 copies). Virus at such levels is replicating so slowly that little if any damage will be happening to your CD4 cells and immune system.

Undetectable viral load does not mean the virus has been eradicated from your body – it just means that the level of virus in your blood

cannot be measured by current commercial tests. The tests available are slowly becoming more sensitive. However, special laboratory tests are able to detect HIV in even minute quantities. HIV infects cells which remain inactive, or 'resting', in lymph glands. This HIV is not reached by treatments. As long as it remains in the 'resting cells' in lymph glands, it does not reproduce or do any damage. But it does mean that HIV is still present in the body. To totally cure or eradicate HIV, you would need to also eradicate the virus in these 'resting cells'.

b) Detectable viral load results

You will often be told that your viral load result is 'high', 'moderate' or 'low'. On their own your viral load results are no cause for alarm. For example, a high viral load result does not mean you are going to be sick tomorrow. Or a low result after your results have been undetectable for some time does not mean you have suddenly "failed" in any way.

Your viral load level is a rough guide to the likelihood of *future damage* to the immune system. So if your viral load is high it means that future damage is more likely. If it is low or undetectable it means future damage is less likely.

In order to make decisions about treatments the viral load has to be read in conjunction with the CD4 cell count. (See *Putting it all together - Viral load and CD4 count results* Page 14)

Viral load and the pattern over time is important

You may be asked to have viral load tests fairly frequently so you and your doctor can keep track of changes over time, or of any sudden variations between test results. In fact, an unexplained and significant upward trend in viral load over a number of tests may be a stronger indicator that you should consider changing or starting drugs than a single, detectable result in isolation. The magnitude of the change is important. For example, a rise of viral load from 5,000 to 6,000 does not necessarily indicate there is a problem. But a rise from 5,000 to 50,000 would suggest that virus is beginning to replicate very rapidly for some reason, and that you should think about starting or changing drugs.

Other factors can affect viral load

No one viral load result should be considered alone. It's the pattern over time which counts. There are a number of reasons why you may experience a sudden temporary rise, or 'spike' in your viral load.

These include:

- another infection (eg. the flu, hepatitis, or another sexually transmitted infection such as gonorrhoea);
- recent vaccination (eg. routine travel-related vaccinations or hepatitis A or B vaccination), which can stimulate your immune system.

Make sure you understand the meaning of your viral load test results. Ask your doctor to explain their significance.

Viral load and women

Some research suggests that women may have lower viral loads than men – particularly in the first few years after infection – but despite these differences women developed AIDS at the same rate as men. However, other research has not found that viral load is different between men and women at AIDS diagnosis. At the present time advisory bodies in the US and Australia responsible for developing HIV treatments guidelines have not recommended different guidelines for men and women. Still, it is important to remember that guidelines are just that, and may not accurately reflect the effect of HIV on each individual. It is important to discuss with your doctor the factors which can affect progression of HIV.

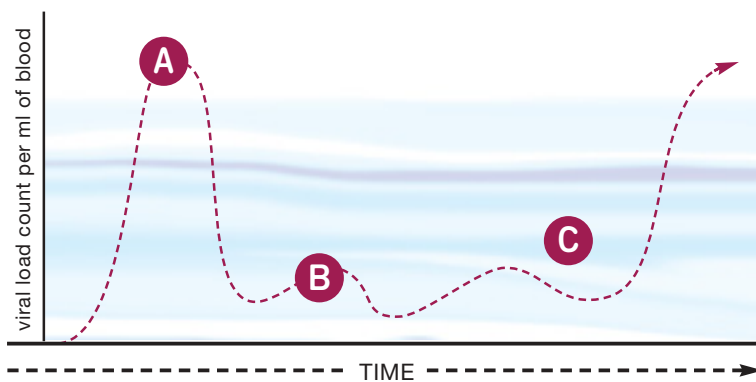
This includes:

- taking *both* viral load and CD4 levels into account;
- being aware of any changes in the way you feel, or any possible symptoms which may suggest immune damage or AIDS-related illness.

Viral load and “infectiousness”

Viral load tests tell you how much virus is in your blood. But HIV is also present in other body fluids, including CSF (cerebrospinal fluid) – the fluid which protects your brain – and semen and vaginal fluids. The level of virus in your blood is often different to the amounts in other body fluids. This difference can be caused by a number of factors. For this reason, blood viral load tests should not be used to judge the likelihood of HIV transmission. It is possible to have low or undetectable blood viral load, but higher levels in semen or vaginal fluids.

Viral load over time without treatment



- A Stage 1:** Seroconversion Very high viral load
- B Stage 2:** No Symptoms Low to moderate viral load
- C Stage 3 + 4:** Symptoms High viral load

The typical picture of viral load over time is given above. Soon after infection there is a peak in viral load until the immune system responds. Then, for a period of years the immune system and the virus are engaged in a balancing act. However, during this period, the virus is still active. Eventually, the virus may overwhelm the immune system.

When you first have your viral load tested, you will usually have two tests 2-4 weeks apart, which gives a result known as your “baseline”, and which can be used to compare changes over time. These results can be a useful guide if you are considering treatment.

If you are not taking antiviral drugs, you will probably be advised to have a viral load test each time you have a CD4 or T-cell count.

Comparing these results with your baseline viral load will alert you and your doctor to any changes in your immune system or your health.

Ask your doctor to explain the meaning of any changes in your viral load. It is quite common for viral load to change a bit with each test. What is important is the magnitude of the change. Doctors use a mathematical scale called a logarithmic scale to measure the significance of any changes. It is only changes of a significant magnitude that are considered important. This means, for example, that a rise from 1,000 viral copies to 2,000 copies is not very significant on this scale; but a rise from 5,000 to 50,000 from one test to the next would be important and could suggest you need to start or change treatment.

To get the best picture, CD4 and viral load test results should be considered together.

The CD4 count

The other test that is critical in managing HIV and understanding how it is affecting you and your body, is the CD4 or T-cell count.

CD4 cells are a critical part of your immune system. They are infected and destroyed by HIV. Sometimes, they can be depleted to such dangerous levels that they are unable to play their part in helping your immune system work properly. If this happens, you could be at risk of developing AIDS or AIDS-related illnesses.

CD4 counts used to be the only way to understand how HIV was affecting your immune system. The CD4 count is a measure of the damage already done. The viral load is a measure of the risk of future damage.

A general guide to CD4 test results is:

- 500 to 1,350 CD4 is the “normal” range for adults;
- more than 500 CD4 indicates little or no immune system damage;
- between 500 and 250 CD4 cells indicates some damage but it is unlikely you will be at risk of major opportunistic infections;
- less than 250 CD4 indicates more serious immune system damage and suggests that you could be at risk of serious opportunistic illnesses.

Putting it all together – Using viral load results and CD4 count results to inform treatments decisions

To get the best picture, CD4 and viral load should be considered together. The viral load test and CD4 count can be used to determine:

- the level of activity of the virus in your bloodstream;
- the level of damage to your immune system;
- when to start antiviral treatments;
- if the current antiviral treatments are working, and whether it may be necessary to change treatments; and
- when to take preventative medicines (prophylaxis) to decrease the chances of getting some of the more common opportunistic illnesses associated with AIDS.

When the effectiveness of multiple combinations of antiviral drugs was proven, the HIV antiviral treatments guidelines were ‘hit hard, hit early’. The belief was that most people could benefit from suppressing the viral replication. As experience with the drugs grew there became increased knowledge about some of the longer-term toxicities associated with these drug combinations. The theoretical advantage of early treatment to maintain immune function has to be weighed against the toxicities of long-term exposure to anti-retrovirals.

The current treatment guidelines (as of 2001) recommend commencement of treatment whenever:

- There are symptoms of HIV disease
- There is neurological HIV disease
- The CD4 count drops below 200
- Women with HIV are pregnant (in order to reduce the risk of transmission)

And

- Where the baseline CD4 cell count and viral load levels indicate a significant chance of disease progression in the absence of treatment. (see the table below)

The recommended treatments guidelines in Australia are updated regularly. They were last revised in 2001 and are currently under review as at the middle of 2003. Your local AIDS Council or PLWA group or ASHM (The Australasian Society for HIV Medicine) should have the latest guidelines. These guidelines are based on a combination of CD4 results and viral load test results.

Risk of AIDS in 6 years (%)

Viral Load	CD4 Count		
	< 350	350 - 500	> 500
> 55,000	93	79	67
20,000 - 55,000	73	57	50
7,000 - 20,000	42	40	26
< 7,000	19	22	15

* *Bold equals 'risk of AIDS in six years' greater than 50 percent, therefore treatment is recommended.*

Common tests for monitoring for side effects

Viral load and CD4 cell count results are two of the main tests used to inform treatment decisions about starting or changing treatments. Usually every time you have regular blood tests a whole range of tests are done. Some of these are useful in monitoring for possible drug side effects and potential organ damage. The results of these tests may also influence decisions to change HIV antiviral treatments.

Some of the common tests include:

Cholesterol and triglyceride levels: The two major fats (lipids) in the blood are triglycerides and cholesterol. Glucose, triglyceride, and cholesterol levels are most reliably measured in the fasted state, that is in the morning before eating. Certain combinations of anti-HIV therapies are thought to increase cholesterol, triglyceride, and glucose levels in some persons, which may increase the risk of heart attack and stroke, and can be a sign of lipodystrophy.

Liver function tests: There are a range of tests which taken together give an indication of the health of the liver. The liver can be damaged by hepatitis, alcohol and other drugs, and by HIV antiviral drugs directly – so it is important to keep a watch on liver function.

Kidney function: Kidney function is normally measured by the levels "waste" products such as uric acid and creatinine. Some HIV antiviral drugs can affect the levels of these waste products because they compete with them for excretion in the kidney. Some HIV antiviral drugs may have an impact on kidney function.

Platelet count: Platelets are important in helping your blood clot in response to a cut or wound. Some HIV antiviral drugs – particularly nucleoside analogues (eg. AZT, d4T) – can decrease the platelet count.

Haemoglobin and Haematocrit: Haemoglobin measures the levels of the key protein which transports oxygen around the body. Haematocrit is a measure of the proportion of blood that is red blood cells. Low haemoglobin levels or a low haematocrit can be an indicator of anaemia – a known side effect of some HIV antiviral drugs.

Other tests which may help inform treatments decisions

Resistance testing:

If it was possible to have accurate information about which drugs you were resistant to and which drugs you were sensitive to, then this would be useful in determining your optimal treatment strategy. Resistance testing is still expensive, and the best ways to use and interpret resistance assays is still not totally clear – so they are not yet part of routine management. However, in some international studies, patients whose treating doctors received information on the existing mutations before the therapy was changed usually had more significant decreases in the viral load than patients in whom treatment was changed without knowledge of the resistance profile.

Therapeutic drug monitoring (TDM):

If you are on some new HIV antiviral treatments and your viral load isn't going down as far as expected, it might be because drug levels are too low. It may be possible to increase the dose. If you are having serious side effects, it might be because drug levels are too high. If they are, a smaller dose might still control HIV but relieve some side effects. It is possible to test for the blood levels of some (but not all) HIV antiviral drugs. This is usually done by doing a blood test just before taking the next dose of pills and measuring the drug level. This measures what's known as the trough level of the drug. Not all individuals are the same. It is hoped with TDM to be able to individually tailor doses where particular problems are identified. However TDM is still a relatively new test in HIV management and more research needs to be done in order to identify the best ways to use the results.

3 three

Antiviral treatments

Combination therapy

Combination therapy means taking a combination of antiretroviral drugs. Often, they're just referred to as antivirals. There are currently four types or classes of these drugs, each of which work in different ways against HIV. It is now known that the most effective way to treat HIV is by combining different classes of drugs that attack the virus in different ways.

It is now standard practice to have people on a combination of at least three drugs from two of these classes, or more. Note that some companies who make two or more different drugs that can be used in combination are sometimes combining these drugs into one pill. So sometimes you may be on only two different sorts of pills but three different drugs.

The number of different drugs that you are on can be:

- **Monotherapy or one drug:** this is generally considered harmful as experience shows benefits may be short lived and resistance usually develops rapidly. Resistance to one drug may limit your future treatment options.
- **Two drugs:** Usually two drugs is not considered sufficient when you first start treatments. Two drug combinations are usually only used because you have experienced severe side effects or sometimes as second line therapy after you have kept the virus suppressed for some time with your first treatment combination.
- **Three or more drugs:** This is considered the general rule particularly when starting treatment.

Overwhelmingly, standard practice is three drugs in combination – widely supported by existing research and international guidelines. If your doctor suggests you start or remain on just one or two drugs, find out why. If you're not satisfied with the explanation, or you think your doctor may not be up-to-date, seek a second opinion. "You're doing OK so far on just one drug" (for example) might be one answer which suggests a second opinion may be useful.

The four classes of drugs are:

- nucleoside reverse transcriptase inhibitors (or "nukes") - nucleoside analogues and nucleotide analogues;
- non-nucleoside reverse transcriptase inhibitors (non-nukes or NNRTIs);
- protease inhibitors (PIs); and
- fusion or entry inhibitors

The most common combinations include two nucleoside reverse transcriptase inhibitors, in combination with either a non-nucleoside reverse transcriptase inhibitor or a protease inhibitor.

The changing face of treatments strategies

Multiple combinations of HIV antiviral drugs were first shown to be highly effective in combating HIV in the mid 1990's. They were referred to as Highly Active Antiretroviral Treatments or HAART. The recommended treatment strategy was 'hit hard, hit early'. There was hope that HIV could be completely eradicated from someone's body. As knowledge about HIV in the body expanded it became clear that HIV eradication would not be possible with these drugs. As experience with these drugs grew, knowledge about their long-term side effects grew. The goals of treatment strategies changed from viral eradication to one of maximising antiviral benefit while attempting to minimise HIV antiviral drug side effects.

Because of the changed goal of treatments a number of different strategies are now recommended or being tested.

These include

1. Different ways to use existing drugs:

- Changing the treatment guidelines away from 'hit hard, hit early'. (see 'when to start' below)
- Introducing *second line therapy* involving potentially less harmful combinations after the first line (i.e. the first) therapy has successfully suppressed the virus for some time.
- Incorporating *structured treatment interruptions* (often referred to as *treatments breaks*) involving a period of time off treatments and then recommencing after a pre-determined time period or pre-determined viral load or CD4 cell count. As of 2003 there are no recommendations about structured treatment interruptions as different strategies are being extensively trialed internationally.
- Testing new combinations of existing drugs because of their different side effect profiles. For example, if someone has drug toxicities due to the nucleoside class of drugs then effective combinations that do not involve nucleosides would be useful. These combinations are often referred to as '*nucleoside sparing*'.

2. Looking for new drugs such as:

- Drugs of the same classes with better side effect profiles or different resistance profiles or that are more active.
- Completely new classes of drugs such as the fusion or entry inhibitors (the first entry inhibitor T-20 was approved in the USA in 2003 and is being trialed currently in Australia).

Resistance

Every time HIV reproduces itself there's a high chance that it may 'mutate' slightly. A 'mutation' is a small alteration in the genetic makeup. These alterations may make the virus more resistant to a drug. The more the virus is reproducing (i.e. the higher the viral load) the more chances there are of mutations occurring. If you are on one drug then the virus may only have to mutate in one place for resistance to occur. But if you are on two drugs then the virus has to mutate in two different places at the same time – and there is much less chance of this occurring. Three drug combinations work best because they both stop most virus reproduction and because the chances of a mutation conferring resistance to all three drugs at the same time are very small.

Missing doses regularly may allow the virus to escape the control of a drug.

If you miss doses regularly or stop taking the drugs for a few days you give the virus a chance to mutate. And because small concentrations of one or more of the drugs you are on can still remain in your bloodstream any mutations which are resistant to these drugs will multiply better and have more chances of then infecting new cells. And each missed dose can mean slowly rising levels of resistant virus in your body. Missing doses regularly may allow the virus to escape the control of a drug.

If the virus does develop resistance the drugs become much less effective. If this happens, HIV can keep multiplying in spite of the drugs, effectively behaving as untreated virus. This is why rises in viral load can mean you need to change drugs.

A few tips to help stop the development of resistance

- Take the full dose of each drug, as prescribed. This allows the drug always to be working at maximum capacity.
- If you miss a dose, don't double up on your next dose. You just risk more side effects but won't have a better result against the virus.
- Take all the drugs in your combination regularly. This means the drug is always in your blood and at levels that work effectively against the virus.
- If you are having difficulties taking a certain drug because of side effects or dose requirements, consider changing to a combination that suits you better and is easier to remember. It is better to change treatments than to stay on a combination which doesn't suit.

When to start?

The answer to the question of 'when to start' varies according to the stage of your HIV disease or if there are special reasons for starting.

A. For people with recent HIV infection

i.e. you had a recent seroconversion illness or you have had a recent positive HIV-test and tested HIV-negative in the previous twelve months. There are particular components of the immune system that are lost relatively early in HIV disease. It is thought that once the body's own immune response to HIV is established it may be able to prevent these important components being lost. The goal of treatment is to preserve those vital components of the immune system until the body's own immune response to HIV is established. It is thought that preserving these components may improve the body's own ability to control HIV by itself. It is still too early to say whether this strategy will result in a long term advantage compared to starting antiviral therapy at a later stage. The potential downside of early treatment includes difficulties in taking some combination therapies. Additionally, the emerging issue of long term side-effects have led some to question if they should or need to treat at this time.

B. For people with chronic HIV infection who remain "well"

The current treatment guidelines (as of 2001) recommend commencement of treatment whenever the baseline CD4 cell count and viral load levels indicate a significant chance of disease progression in the absence of treatment. (see the table "risk of AIDS in 6 years" already shown on page 15). Here the goal of treatment is to prevent progression of HIV disease and the development of symptoms of HIV disease.

Think about whether you're ready to integrate combination therapy into the way you live

C. For people with chronic HIV infection who have symptoms of HIV disease

Treatment is recommended for any person with symptoms of HIV disease including neurological HIV disease. The goal of treatment is both improvement in health and the prevention of further damage to the immune system.

D. For women who are pregnant

Treatment is recommended in the third trimester of pregnancy. Here the goal of HIV antiviral treatment is to reduce HIV viral load and therefore decrease the chances of vertical transmission from mother to baby.

Starting antiviral therapy is a serious commitment because it may mean taking drugs for the rest of your life. Any treatment decision needs to be discussed fully with your doctor, taking into account not only viral load and CD4 but most importantly, your ability to integrate combination therapy into the way you live.

What combinations are best?

There are lots of possible combinations of HIV drugs. It's not possible to describe them all in this booklet. Further, people will respond differently to the same combinations, for a variety of reasons. Just because something worked for a friend doesn't mean it will work for you, and vice versa. There are many factors affecting individual responses to HIV and therapy.

Are you having trouble with your dosing schedule?

Some drugs can't be used in combination for scientific reasons (eg. they compete with each other to get absorbed into the body), or other reasons (eg. they have the same side effect, and may increase your risk). Work with your doctor to choose the best drugs, considering some of the factors listed below.

- What stage of disease are you at (viral load, CD4 count, symptoms)?
- What prior treatment, if any, have you had?
- What treatments are you on now?
- How easy will it be to take the particular combination?
- What are the possible side effects?
- Does your job make it hard to remember to take medication in the middle of the day?
- Do you have a busy life and eat at different times every day?
- Are there confidentiality issues around taking drugs regularly?
- Would you have trouble taking a drug that needs to be refrigerated?
- Do you travel a lot?

Australian HIV treatment guidelines are updated every few years and may contain recommendations about which drugs or combination of drugs to take in particular circumstances based on the latest evidence. These are available from the AIDS Councils and PLWHA groups listed on page 34 - 35 of this booklet.

Compliance

Compliance (also referred to as "adherence") means the extent to which you take the right dose of the drugs at the right time. Taking the right dose at the right time is important. Skipping doses can mean that the drug becomes ineffective against the virus. Taking a drug on a full stomach when it's meant to be taken before eating can make the drug less effective. Make sure you know how each drug should be taken to be as effective as possible against the virus.

There are plenty of ways to help you remember to take your drugs on time. You could experiment with some of these.

- Take your drugs at the same time each day.
- Have supplies of your drugs at places you know you'll be (partner's house; work, if relevant).
- Take your drugs with you wherever you go.
- When travelling, be aware of the different time zones you might be crossing and adjust your dosing times accordingly (this can be done by talking to your doctor before you leave).
- Portable pill boxes, with a timer that you can set to beep each time you need to take a drug, are generally available from your doctor.
- Get a dosette box – this is a box which lets you set out your pills for the week in labelled sections so you can easily see what you have taken and what you need to take next. These are available from chemists.
- Keep a calendar or diary in a prominent place at home and work which you can tick off each time you take your pills.
- Establish a routine which associates pill taking with meals where appropriate.
- Get an electronic diary and program it to remind you to take the drugs.
- Prepare for holidays by getting a stock of drugs in advance.
- Find out from other people with HIV what they do to help remember their pills.

Monitoring and changing combinations

You may need to change your drugs for a number of reasons. If there are sudden unexplained changes to your CD4 count or viral load it could mean that the virus has become resistant to one or more of the drugs in your combination.

You may also need to change combinations if you are unable to meet the requirements for dosing schedules, or if you are finding the side effects intolerable, even if your viral load and CD4 levels are OK.

If you have been on a three drug “first line” combination for some time and successfully suppressing the virus your doctor may recommend you changing to “second line” combination. Because you have suppressed the virus for a long period then it may be now easier for a less potent combination to keep the virus suppressed. This less potent combination may be associated with less long term side effects.

If you have been experiencing severe side effects due to a particular drug or class of drugs there may be other combinations that do not include this drug or classes of drugs that can be recommended. Australian HIV treatment guidelines are updated every few years and may contain recommendations about which drugs or combination of drugs to take in particular circumstances based on the latest evidence. These are available from the AIDS Councils and PLWHA groups listed on pages 34 - 35 of this booklet.

You will need to be monitored after each change in combination to see how the new combination is working. During these times, you will probably need more frequent viral load tests.

Treatment breaks

A separate booklet called *HIV Treatment Breaks* examining all the issues associated with HIV Treatment Breaks is available from your local AIDS Council or PLWHA group.

Combinations of three or more HIV antiviral drugs were shown to be highly effective in treating HIV disease in 1996. At the time it was hoped that after long periods on these drugs it may be possible to ‘eradicate’ HIV from the body. In 2003 it is now known this is not possible with the current treatments. For some people there are significant toxicities associated with using the current drugs for long periods. It is not surprising then that one possible strategy being examined to minimise long term side effects while attempting to maximize the length of antiviral benefit is the possibility of taking a break from your anti-HIV treatments.

There is still not a lot of good data about whether treatments breaks may be of benefit to people with HIV in the long term and how you may be able to predict which people with HIV (based on stage of HIV disease and viral load and CD4 count) are more likely to benefit.

At the current time:

- The benefit of “structured treatment breaks” has not yet been established in any setting and stopping therapy involves a number of potential risks.
- Taking a treatment break should be done in partnership with your medical practitioner(s). Even if you started a break without telling your medical practitioner informing them and monitoring your health and immune system is very important.
- Everyone is different – there is not one simple answer to the question of ‘Can I safely take a break from my HIV treatments’.

Except in very particular circumstances, the research shows overwhelmingly that after stopping treatment, HIV starts to reproduce again, and consequently, CD4 cells decline. This is particularly so for people who have already had low CD4 counts, or AIDS-defining illnesses, in the past.

Do you need a rest from HIV drugs? It's important to discuss breaks with your doctor.

Sometimes, people stop treatments for just one or two days, eg. during a Mardi Gras party weekend or a camping trip. This is often referred to as a “drug holiday”. Stopping treatments for just one or two days could put you at real risk of developing resistance. There is some research to suggest that stopping drugs for short periods of time, or regularly missing some doses may be more risky in terms of resistance than stopping all drugs at once for a longer time (eg. a month). This is because different drugs remain active in your system for different periods of time between doses. You should not stop your drugs for these very short periods.

However, some people do feel the need to take longer, planned breaks from HIV drugs. This may be because of side-effects, the desire to “have a rest”, or other factors like overseas travel. You should discuss this thoroughly with your doctor. Factors like viral load and CD4 are very important. If you have a very low CD4 count, stopping treatments could put you at risk of opportunistic illnesses. You should consider whether you need prophylactic treatment during this time, particularly (but not only) if you have ever had an AIDS-defining illness or opportunistic infection (eg MAC or PCP).

If you do want to stop your drugs for whatever reason, you could devise a plan with your doctor, including:

- whether you might need prophylactic treatment during this time;
- how long a break;
- at what point, if any (eg. viral load, CD4 count) you would consider starting treatment again;
- how you feel about monitoring, blood tests, etc. during this period.

Some doctors feel that if a person is having major trouble with adherence, and missing doses, taking their drugs erratically etc, it may be more sensible to stop all the drugs and work through these problems over time, before trying again.

Side-effects

A detailed information booklet on the side effects of HIV & antiviral drugs (called “Managing side effects”) is available from your local AIDS Council or PLWHA group.

Any drug can cause side-effects, or unwanted effects. These can be divided into different types: allergic reactions and short-term side effects; ongoing side effects; and long-term toxicities or effects which can develop over a number of years. Not everyone gets side effects from their drugs. Not everyone experiences the same side effects. Many are quite rare.

Your doctor should inform you of possible side effects - if not, ask!

It’s hard to estimate how often people develop different side effects. Estimates and studies show varying figures. All anti-HIV drugs are known to cause diarrhoea and gastrointestinal upset to some degree, but this side effect is often easily managed. If you start treatment with a low CD4 count or viral load, side effects may be more of an issue, and need pre-planning for effective management.

Allergic side-effects can occur when the immune system reacts badly to a drug, causing symptoms like rash or fever. Often, these symptoms will resolve themselves, but if you develop a rash when beginning a drug, seek medical advice because on rare occasions, reactions can be dangerous. You may be able to treat rash with antihistamines, or by slowly increasing your dose as your body gets used to the drug.

Direct reactions to the drugs can cause a range of sometimes ongoing side-effects which can vary from mild (headache or occasional diarrhoea) to more serious. There are also some problems which may develop over time, like numbing of the fingers and toes, abnormalities in liver function, or abnormal redistribution of fat throughout your body.

Some of the more common side effects are associated with starting on treatment and many of these pass rapidly or after a short time on treatment.

Your doctor may prescribe other medicines (like anti-diarrhoea drugs) to help deal with some of these. Your doctor should inform you of the more common side effects. Many people report that some simple complementary therapies are useful in controlling side-effects: talk to an HIV-experienced dietician for advice. Referrals will be available through your doctor or AIDS Council treatments officer.

Some side effects to HIV drugs can develop over the long-term. Now that we know more about these drugs, doctors are increasingly monitoring and checking for signs of these problems, and may advise you to change drugs if you are at risk. These include:

- peripheral neuropathy, or nerve damage causing pain in hands or feet;
- blood sugar changes;
- high cholesterol or blood fats;
- body shape changes like fat wasting or developing a belly, paunch or enlarged breasts (lipodystrophy);
- muscle inflammation;
- anaemia;
- hepatitis and pancreatitis;
- mouth ulcers.

The earlier you detect any changes, the easier it is to make changes to diet, exercise or the drugs themselves, which can all help improve – or in some cases reverse – these effects.

Salvage Treatment

Some people with HIV who have years on treatments and have been on lots of the antiviral drugs may have special problems in switching their antiviral medications because they are resistant to most types of drugs. Treatment strategies for people who appear to have HIV that is resistant to many of the available drugs are often referred to as salvage therapy.

There are three different salvage therapy strategies that may be tried:

- Recycling drugs – that is using drugs you have previously used done in concert with resistance testing to determine which ones may work best.
- “Mega-HAART” regimes – using combinations of up to nine antiviral drugs – these regimes of course may pose serious side effect problems.
- “Treatment Intensification” – adding one or two drugs to an existing regime.

Sometimes none of these strategies may be suggested or you may choose not to try them because of the side effects. Even if you are on a regime to which you appear to be somewhat resistant your doctor may recommend you continue on it as it still may provide some protection.

Other treatments

HIV causes different effects in different people. No two people with HIV have exactly the same experience of any side effects, illnesses or symptoms, though there are some common stories. At some times, you may need to take other drugs, like antibiotics, for specific infections or symptoms.

You will need to find out from your GP, pharmacist or specialist whether these interact with the combination therapies you are on.

There are some good resources around to help you understand the treatments you are on. These are available online at www.afao.org.au.

Re-infection (superinfection) with HIV

Re-infection means someone getting a new or secondary infection from a virus that has already infected them. In some viral diseases re-infection does not occur because the original infection creates immunity. In other viral infections such as the cold and flu re-infection occurs frequently – because of the different strains of the virus.

Whether re-infection can occur with HIV was hotly debated. Many thought it was a theoretical possibility – it just hadn't been observed. That was until 2002 when three well documented cases of HIV re-infection were described.

There are many questions about what HIV re-infection means. We don't know what impact it may have on disease progression. We don't know what impact re-infection with strains of HIV that are resistant to HIV antiviral drugs will have.

We also do not know how often re-infection occurs. It is quite hard to identify and prove so even though it has not been observed frequently it may actually occur more often.

What we do know is that re-infection has gone from a theoretical possibility to a real occurrence. People with HIV may become re-infected through unsafe sex or injecting with other people with HIV. They should factor the changing information about re-infection into the choices they make.

Illicit drugs

There's not a lot known about how HIV drugs interact with illicit or recreational drugs, though this is changing. However, if you do take recreational drugs, there are some common cautions you could follow. Avoid taking HIV drugs and other drugs at exactly the same time: wait at least a couple of hours between doses.

- Ritonavir, and possibly other protease inhibitors, may cause dangerous, even fatal interactions with ecstasy, methamphetamine and other amphetamines.
- Drink plenty of water.
- Start with a smaller amount of any illicit drug and monitor any unusual responses.
- Seek emergency medical help if you experience dizziness, sudden drowsiness, blurred vision, heart palpitations, vomiting or any other severe or unexpected effect.

Immune-based Therapies

Most of the recent attention in HIV research has focused on treatments that attack HIV itself, or work against the virus in the body. However, there is a significant move towards looking at ways to prevent, treat or repair immune system damage caused by HIV. This makes sense, because it is not HIV itself, but the damage the virus does to the immune system, which puts people at risk of illness and death.

Approaches to managing or treating HIV immune system damage are called immune-based therapies or immune modulators.

At this stage, there are no immune-based therapies licensed to treat HIV. However, a number of experimental treatments are being examined. Many people believe immune-based therapies will still need to be used in combination with antiviral drugs, but may mean that antiviral drugs need only be used infrequently or sporadically, rather than every day.

Interleukin-2 (IL-2) is the most advanced of the immune-based therapies. There is currently a large-scale clinical trial of this drug being conducted at sites all around the world, including a number of sites in Australia. IL-2 has previously been shown before to increase the production of CD4 cells. The trial hopes to show that these cells function well, and have a protective effect on the immune system.

Other immune-based therapy approaches include therapeutic vaccines, designed to stimulate the immune system's ability to directly fight HIV.

New research in this area continues.

Support services contact details

(* TTY services available for the hearing impaired)

AIDS Councils

Australian Capital Territory
AIDS Action Council of the ACT
Tel: (02) 6257 2855

New South Wales
AIDS Council of NSW

Sydney Office
Tel: (02) 9206 2000
TTY* (02) 9283 2088
Freecall 1800 063 060

Positive Living Centre (Sydney)
Tel: (02) 9699 8756

Western Sydney
Tel: (02) 9204 2400

Hunter (Newcastle)
Tel: (02) 4927 6808

Illawarra (Woolongong)
Tel: (02) 4226 1163
(Resource Centre)

Tel: (02) 4229 2944
(Multi Purpose Centre)

Mid North Coast
(Port Macquarie)
Tel: (02) 6584 0943

Northern Rivers (Lismore)
Tel: (02) 6622 1555

Northern Territory
Northern Territory AIDS and
Hepatitis Council
Tel: (08) 8941 1711
Freecall 1800 880 899

Western Australia
Western Australian AIDS Council
Tel: (08) 9482 0000

South Australia
AIDS Council of South Australia
Tel: (08) 8362 1611
TTY* (08) 8362 0306
Freecall 1800 888 559

Tasmania
Tasmanian Council on AIDS
Hepatitis & Related Diseases
Tel: (03) 6234 1242
Freecall 1800 005 900

Queensland
Queensland AIDS Council

Brisbane
Tel: (07) 3017 1777
Freecall 1800 177 434

Cairns
Tel: (07) 4051 1028

Gold Coast
Tel: (07) 5575 6966

Sunshine Coast
Tel: (07) 5441 1222

Townsville
Tel: (07) 4721 1384

Victoria
Victorian AIDS Council/
Gay Men's Health Centre
Tel: (03) 9865 6700
Freecall 1800 134 840
TTY* (03) 9827 3733

PLWHA Groups

Australian Capital Territory
PLWHA ACT
Tel: (02) 6257 4985

New South Wales
PLWH/A NSW
Tel: (02) 9361 6011
Freecall 1800 245 677

Positive Heterosexuals
Tel: (02) 9515 3095
Freecall: 1800 812 04

Northern Territory
Friends NT
Tel: (08) 8941 7711

South Australia
PLWHA SA
Tel: (08) 8293 3700

Tasmania
C/- TasCAHRD
Tel: (03) 6234 1242

Victoria
PLWHA Vic
Tel: (03) 9865 6772

Queensland
Allen St Centre Brisbane
Tel: (07) 4041 3061

Qld Positive People
Brisbane
Tel: (07) 30171759
Freecall 1800 636 241

Cairns
Tel: (07) 4041 3061

Gold Coast
Tel: (07) 5575 6966

Sunshine Coast
Tel: (07) 5441 1222

Rockhampton
Tel: (07) 4938 7720

Mackay
Tel: (07) 4953 5071

Townsville
Tel: (07) 4721 1384

Western Australia
H.A.P.A.N.
Tel: (08) 9482 0000

Services for Women

AIDS Council of NSW: Women,
HIV and Health Promotion
Tel: (02) 9206 2015

Positive Women Victoria
Tel: (03) 9276 6918

HIV Women's Project of SA
Tel: (08) 8267 5366

Paediatric AIDS Unit,
Prince of Wales Hospital (NSW)
Tel: (02) 9382 1654

Services for Heterosexuals

HIV Positive Heterosexuals
(PozHets)
Tel: (02) 9515 3095
Freecall: 1800 812 404

Straight Arrows (men only)
Tel: (03) 9276 3792

Positive Living Centre
(South Australia)
Tel: (08) 8293 3700

Services for Current and Past Injecting Drug Users

ACT
Directions - ACT
Tel: (02) 6248 7677

NSW
NSW Users and AIDS Assn.
Tel: (02) 8354 7300
Freecall: 1800 644 413

Northern Territory
TUF
Tel: (08) 8941 2308
NSP
Tel: (08) 8941 1711

Victoria
Victorian Drug User
Organisation
Tel: (03) 9419 3633

Queensland
Gold Coast DUNES
(Drug Users Network Education
& Support)
Tel: (07) 5520 7900

Sunshine Coast Injectors
Voice and Action Association
Tel: (07) 5443 9576

South Australia
SAVIVE (SA Voice for
Intravenous Education)
Tel: (08) 8362 9299

Tasmania
C/- NUFIT
Tel: (03) 6272 7892

Western Australia
WA Substance Users
Association
Tel: (08) 9227 7866

Services for Sex Workers

ACT
SWOP
Tel: (02) 6247 3443

NSW
SWOP Sydney
Tel: (02) 9319 4866

SWOP Hunter
Tel: (02) 4927 6808
SWOP Illawara
Tel: 0407 900 341

Northern Territory
SWOP
Tel: (08) 8941 7711

Queensland
SQWISI Brisbane
Tel: (07) 3844 4565

SQWISI Cairns
Tel: (07) 4031 3522

SQWISI Gold Coast
Tel: (07) 5531 7833

SQWISI Townsville
Tel: (07) 4721 3434

South Australia
SA Sex Industry Network
SWOP
Tel: (08) 8362 5775

Tasmania
C/- SWOP
Tel: (02) 9319 4866

Victoria
RHED
Tel: (03) 9534 8166

Western Australia
Magenta
Tel: (08) 9328 1387

Glossary

Adherence

Often shorthand for 'strict adherence to therapy', meaning pills are taken exactly as prescribed – on time, every time, and observing any specific dietary requirements. Also referred to as 'compliance'.

Antiretroviral

A more complex term for antiviral drugs, in this case, any drugs which are designed to inhibit the process by which HIV replicates. In this booklet, the simpler term antiviral is used, and it is assumed that the virus in question is HIV. The more technical term antiretroviral refers to the fact that HIV is a retrovirus.

CD4 cells (also: T-cells or T-helper cells)

A type of blood cell involved in protecting the body against viral, fungal and protozoal infections. CD4 cells are part of the human immune response. If HIV is inside the human body, it targets, and replicates within, CD4 cells, destroying them in the process. The cells are so named because they have a particular marker, known as a CD4 receptor, on their surface. CD4 cells are sometimes called the 'conductors' of the immune system, since they orchestrate the responses of other cells.

Clinical trials

Studies which test experimental medicines in humans, in order to establish that they are safe and effective. Clinical trials are staged in 'phases', beginning with small numbers of people, then being tested more widely as data on safety and efficacy is established.

Compliance

See adherence

Drug holiday

Refers to "breaks" from antiviral therapy. Should be distinguished from structured interruptions to therapy under medical conditions.

HAART

Highly active antiretroviral therapy. Usually means a combination of at least 3 HIV antivirals from at least two of the four classes of anti-HIV drugs available: Nucleoside analogues, non-nucleoside reverse transcriptase inhibitors, protease inhibitors and fusion inhibitors.

Immune-based therapies

Anti-HIV treatment which aims to improve, maintain or extend the capacities of the body's immune system against HIV infection, or other diseases. This usually means maintaining a functional immune response in the presence of HIV, or repairing/improving immune response if HIV has already caused damage. Immune-based therapies include therapeutic vaccines and IL-2.

Lipodystrophy

Any disturbance in the normal distribution or metabolism of fat throughout the body. Thought by many to be associated with the use of protease inhibitors. Fat deposits tend to be located on the stomach or upper back. The related term 'lipoatrophy' refers to the loss of body fat from the face and extremities (arms and legs).

Liver

A large gland, dark red in colour, situated in the right side of the upper abdomen. The liver has a number of functions, including: storing and filtering blood, secreting bile, and numerous functions to do with the processing and breaking down of food into energy.

Prophylaxis

Prescribing a drug which is known to prevent an infection from taking hold at a time when a person may not be infected, but is at risk of developing that infection or illness.

Resistance

The ability of a micro-organism like HIV to escape the control of the drugs used to fight it. In terms of HIV, this happens when the virus mutates during the replication process. Viruses like HIV, which have their genetic material encoded in RNA, lack critical genetic 'proofreading' mechanisms. So when new copies of HIV are created, often, minute errors in the genetic translation will occur. Over time, HIV may develop small changes to its structure which mean that anti-HIV drugs, which are designed to interfere with the virus in quite specific ways, will not be able to control it.

Resistance test

A test which looks at the genetic structure of HIV, to determine if any mutations in the virus would make it likely to be resistant to particular antiviral drugs. Sometimes referred to as resistance assays.

Reverse transcriptase

An enzyme which occurs in the family of viruses known as retroviruses, which includes HIV. The enzyme activates the process by which HIV changes its genetic information from RNA (in which it is encoded) into DNA, another form, which allows the genetic information of HIV to be integrated into the genetic material of a host cell (eg, a CD4 cell). Once inside this cell, HIV is able to replicate.

Reverse transcriptase inhibitors

A kind of drug which works to inhibit HIV by interfering with the enzyme which allows reverse transcription, described above, to occur. If reverse transcription cannot occur, or is made difficult, HIV will not be able to replicate, or its ability to do so will be diminished. There are two kinds of HIV reverse transcriptase inhibitor: the nucleosides (either called nucleoside or nucleotide analogues), and the non-nucleosides.

Vaccine (preventative)

An agent introduced into the body which mimics a particular bug or infection in order to trick the immune system into developing immunity against that bug.

Vaccine (therapeutic)

An agent introduced into the body which is designed to stimulate an immune response to a virus or infection that is already in the body.

Viral load

The amount of virus present per cubic millilitre of blood. This is measured by a viral load test.

Undetectable viral load

Tests currently licensed in Australia cannot reliably detect and quantify virus particles if there are less than 50 per millilitre of blood. An undetectable viral load result does not mean that there is not virus present, or that replication is not occurring. It means HIV is there in levels too low to accurately measure.

Drug	Class	Possible side effects	Tips and tricks	Times per day	Food requirements
abacavir (Ziagen)	NRTI	severe hypersensitivity reaction on starting therapy (about 3 percent of people), nausea, vomiting, diarrhoea, fatigue, lack of appetite	Never re-use this drug if you have had a hypersensitivity reaction. In first 2-3 weeks on, see your doctor if immediately you experience: fever, rash, vomiting, nausea, chills, itch, headache	1 x 300mg tablet 2 times a day	With or without
AZT, zidovudine (Retrovir)	NRTI	nausea, vomiting, headache, insomnia, muscle pain, muscle wasting, anaemia (or low platelets), loss of facial and limb fat (Lipoatrophy)	Start at low dose and increase over 1-2 weeks	2 x 100mg capsules 3 times a day or 1 x 250mg capsule 2 times a day	With or without
ddC, zalcitabine (Hivid)	NRTI	mouth ulcers, peripheral neuropathy, loss of facial and limb fat (Lipoatrophy), pancreatitis, night sweats (less than 1%)		1 x 0.75mg tablet 3 times a day	With or without Absorption decreased with food
ddl, didanosine (Videx)	NRTI	diarrhoea, loss of facial and limb fat (Lipoatrophy), pancreatitis (rare)		2 x 100mg tablets 2 times a day	Take on an empty stomach at least 30 minutes before or 2 hrs after food
ddl, didanosine (Videx EC)	NRTI	diarrhoea, loss of facial and limb fat (Lipoatrophy), pancreatitis (rare)		(Videx EC – 1 x 400mg capsule once daily or 1 x 250mg capsule once daily)	Take on an empty stomach at least 30 minutes before or 2 hrs after food
d4T, stavudine (Zerit)	NRTI	peripheral neuropathy, pancreatitis (rare), muscle wasting, loss of facial & limb fat (lipoatrophy) which may be made worse by using some PIs		1 x 40mg capsule 2 times a day or 1 x 30mg capsule 2 times a day	With or without
3TC lamivudine	NRTI	headache, fatigue, insomnia, hair loss (head)		1 x 150mg tablet 2 times a day	With or without
tenofovir (Viread)	NtRTI	Nausea, vomiting, diarrhoea, kidney problems (rare)	Important to monitor kidney function regularly	1 x 300mg tablet once daily	Preferably with food
AZT & 3TC (Combivir)	NRTI	See separate entries for AZT & 3TC (As the dose of AZT in Combivir in Combivir is higher than AZT alone, AZT side effects may be accentuated)		1 x 150mg / 300mg tablet 2 times a day	
AZT, 3TC & abacavir (Trizivir)	NRTI	See separate entries for AZT, 3TC & abacavir (As the dose of AZT in Trizivir is higher than AZT alone, AZT side effects may be accentuated)		1 x 300mg / 150mg / 300mg tablet 2 times a day	
delavirdine (Rescriptor)	NNRTI	fatigue, diarrhoea, nausea, liver problems, rash, fever	Manage rash with antihistamines if not contraindicated by other drugs	4 x 100mg tablets 3 times a day	May be best with food. Should be taken at least 1 hr away from ddl tablets and antacids

(continued)

Drug	Class	Possible side effects	Tips and tricks	Times per day	Food requirements
efavirenz (Stocrin)	NNRTI	rash, liver problems, raised cholesterol (blood fats), dizziness, disorientation, vivid dreams, fatigue, insomnia	Dizziness, disorientation and related side effects often resolve after 2-3 weeks. Avoid cannabis, alcohol & other psychoactive drugs during initial treatment	3 x 200mg capsules once daily or 1 x 600mg tablet once daily	With or without
nevirapine (Viramune)	NNRTI	Rash (sometimes severe), liver problems, headache, nausea	Rash can be treated by antihistamines if not contraindicated by other drugs. Start at lower doses, and increase over 2-3 weeks	1 x 200mg tablet 2 times a day (starting dose: 1 x 200mg tablet once a day for first 14 days)	With food
amprenavir (Agenerase)	PI	Headache, nausea, rash, diarrhoea, tingling around mouth		8 x 150mg capsules 2 times a day	With or without Avoid taking with high fat meals
Atazanavir	PI	Headaches, rash, nausea, diarrhoea, elevated blood fats (less than other PIs), 33% of people have increased bilirubin (a pigment found in the liver) which causes jaundice (yellowing of the skin and eyes in 5 – 16% of people, but rarely requires the drug to be withdrawn (1%))			
Indinavir (Crixivan)	PI	Nausea, liver problems, kidney stones, fat accumulation, elevated blood fats, night sweats (infrequently), skin problems including loss of hair (head or body), ingrown toenails	Take one hour before or two hours after eating. Drink extra water. Do not take antihistamines without medical advice. Regularly check and monitor blood fats and sugars	2 x 400mg capsules 3 times a day	Without food, or with very light meal in morning
Kaletra (lopinavir/rtv))	PI	Diarrhoea, headache, mild nausea, dry mouth, mild thyroid elevation, elevated triglycerides (blood fats)		3 x 133.3mg / 33.3 mg capsules 2 times a day	With food
nelfinavir (Viracept)	PI	diarrhoea, fatigue, headache, rash (sometimes severe)	Do not take antihistamines without medical advice. Diarrhoea may be managed with soluble fibre supplements	3 x 250mg tablets 3 times a day	With food
ritonavir (Norvir)	PI	nausea, diarrhoea, vomiting, taste changes, numbness/tingling round mouth, elevated blood fats, liver problems, menstrual irregularities, fat accumulation	Start with low dose and increase over five days. Ritonavir interacts with many prescription and illicit drugs. Avoid especially: ecstasy/amphetamines, antihistamines, sedatives	6 x 100mg capsules 2 times a day	Take with high protein fatty meal*
saquinavir hard gel (Invirase)	PI	Diarrhoea (less so than soft gel), nausea, night sweats (less than 2%)	Do not take antihistamines without medical advice	3 x 200mg capsules 3 times a day (may be taken 2 times a day under certain conditions)	Take with high protein fatty meal*
saquinavir soft gel (Fortovase)	PI	diarrhoea, nausea, fat accumulation, night sweats (less than 2%)	Do not take antihistamines without medical advice	6 x 200mg capsules 3 times a day	With food*

¹ Doses shown here are according to standard recommended doses. Your doctor may prescribe different doses.

* Lower doses may be used if taken with other protease inhibitors.

NRTI: nucleoside inhibitor

NNRTI: non-nucleoside inhibitor

PI: protease inhibitor

Peripheral Neuropathy: nerve damage causing pain, numbness, tingling in hands, feet, wrists.

This damage may be reversed by stopping the drug.

Fat Accumulation: development of fat deposits eg in breasts, belly, shoulders. Part of the lipodystrophy syndrome.

Important note: The list of side effects described above are possible side effects only. Not everyone who takes the drugs will get the side effects described. Many are quite rare, or may develop over a period of months or years. Others may last only in the first few weeks of therapy. A number of the side effects described above (eg. kidney stones) are rare. Some side effects (diarrhoea, vomiting), are fairly commonly reported. However, you may be able to manage, alleviate or even eliminate these side effects with some fairly simple interventions like dietary changes, or over-the-counter medications. Other side effects, like lipodystrophy, may affect people to varying degrees. It's difficult to say accurately who is at risk. Talk with your doctor about monitoring for the possible development of these side effects as part of your routine monitoring. The earlier you detect them, the greater the options for dealing with them.

Regular treatments information

As our understanding of HIV tests and treatments continues to expand, it can be useful to stay abreast of developments. A good way to keep up to date is by reading regular treatments publications like *Positive Living*. *Positive Living* is produced by the National Association of People Living with HIV/AIDS (NAPWA) and is available free either by post or from AFAO's website (www.afao.org.au). *Positive Living* is published in gay & lesbian newspapers around Australia

The following websites may also be useful:

The Body (US):

<http://www.thebody.com>

National AIDS Manual (UK):

<http://www.aidsmap.com>

Canadian AIDS Treatment Information Exchange:

<http://www.catie.ca>

Project Inform:

<http://www.projectinform.org>

Medscape has a very good HIV/AIDS section & posts out updates:

<http://www.medscape.com>

The AIDS Treatments News site has a useful list of links to other treatments sites:

<http://www.aidsnews.org>



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